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Why is it Bad to Have a Disability?

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1 Introduction

The contrast between public views regarding the impact of a disability on human well-being, also aired in scientific discourse, and the views of disabled people regarding their own well-being is considerable. Disabled people often report a high level of subjective well-being, whilst the outside assumption is that they have little reason to feel like this, or that they are rationalising their situation, distorting their perception or degrading themselves (Albrecht and Devlieger 1999). The assumption endorsed in public perception and in scientific discourse—including philosophy and ethics—is that disability generally involves a drastic reduction in overall well-being and that disability not only implies relative disadvantage or affects certain aspects of well-being (e.g. health, mobility or education) but is overall a standard example of a serious detriment in absolute well-being. In what follows I will challenge this assumption. The problem I see in it is twofold. Firstly, disability is often used as a generalisation, without further specification of which disability is meant. I will indicate which disabilities indeed result in a serious detriment in human well-being or even make it impossible to apply the very concept of well-being. Secondly, the assumption that disability leads to a reduction in well-being in absolute terms—again without further specification—is problematic. Even if it is plausible to argue that it is better not to be disabled than to be disabled, and that the impairment to a bodily function or structure does affect elements of a good life (e.g. health), it does not immediately follow that overall well-being is affected in serious ways (Schramme 2013). Again, it is plausible to argue that impairments affect overall well-being. But this alone does not tell us *how much* and in *what ways* well-being is affected. If it did directly follow that overall well-being is affected in severe ways, then every affect on a single element of a good human life would lead to an absolute detriment of well-being. Human well-being is affected by various relative disadvantages and is far from being perfect. However, in order to understand the most pressing questions of justice concerning disability on a theoretical and a practical level, it is necessary to develop an understanding as to which disabilities pose a serious detriment to a human well-being.

The impact of disability on human well-being has a clear significance in two regards. Firstly, the significance is of a theoretical nature. Assumptions about the impact of disability on human well-being shape the form and content of justice theories, for example (Nussbaum 2006). Secondly, a practical significance comes to light when attempts at clarification of the impact of disability on well-being are made on a cultural and social basis, affecting dealings with, and treatment of people with disabilities.[1]

Two points are important. Firstly, I shall concentrate on the issue of which disabilities are detrimental to human well-being, and for which reasons. As in the following part of the paper I concentrate mainly on the bio-statistical side of disability and thus the impairment of bodily functions and structures and their influence on human well-being, I mainly speak of impairments instead of disabilities. I thus highlight the descriptive side of the concept of disability.

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[1] For example, when a view predominates in society that certain disabilities are concomitant with such a bad life that it would be better for those affected to die than to live, then this attitude has a bearing on the lives of those with the disability, e.g. regarding medical care.

Secondly, in order to show which disabilities affect human well-being in a serious way, I rely on a theory of human well-being that is essentially objective, but includes the subjective evaluation of one's own happiness and satisfaction with life as an important element. This conception of well-being—for instance proposed by Nussbaum (2006, 76f.)—presumes that well-being is dependent upon numerous objective criteria. Among these criteria are bodily health and bodily integrity, affiliation, senses, imagination and thought, emotions and practical reason (e.g. being able to form a conception of the good). This view on the good life in turn assumes that well-being as a phenomenon is not subjective. And yet well-being is evaluated by subjects or individuals. For this reason, firstly, the subjective significance attributed by human beings to particular circumstances or goods can differ *without* the phenomenon itself being subjective. And secondly, we can argue that the endorsement of one's own life is an important element of every objective account of well-being.

This view takes two intuitions into account: First, in order to be a good life from a specific individual's point of view, a life has to be endorsed by the subject. It makes little sense to say that a life is a good life for a certain individual if the subject does not accept his or her life as a good one, worth leading.[2] To argue that the individual needs to endorse his or her life is a matter of objective importance. Thus, the subject's happiness and satisfaction with life is one element of a good life. Second, there is no contradiction in claiming that, from an objective perspective, there are good reasons to believe that certain impairments lead to a drastic reduction in objective well-being, *irrelevant* of the view of the individual. In that case, the objectively bad aspects of life outweigh a possible positive evaluation of the subject.

The argumentation runs as follows. Firstly, I advocate a distinguishing of various categories of characteristics, traits or abilities of people. At this point it becomes clear that, in empirical terms, the impact on well-being of certain characteristics, traits or abilities follows relatively stable patterns. Secondly, I explain that we can also distinguish impairments with regard to their impact on human well-being. The content of these first two steps is descriptive and backed by empirical evidence. In a third step, the moral dimension of the argumentation is then revealed. Here I advocate that we should turn to severe, all-encompassing impairments if we wish to understand which impairments involve a massive reduction in well-being, in turn involving serious moral implications. I shall present three approaches which all rise to the challenge of documenting states of being involving massively reduced well-being. The first two approaches will then be rejected in favour of the third, my own. The first approach is that of 'normal species functioning' originally proposed by Boorse (1975), but taken up and connected with arguments of justice by Daniels e.g. (2001),[3] whilst the second, proposed by Buchanan et al. (2000), understands certain abilities as 'general purpose means'. My own proposal advocates comprehending impairments and well-being within the context of a human, not necessarily biological community. The assumption is that impairments are to be seen as massively detrimental to human well-being when we can no longer imagine a human community which believes fundamental well-being still to be possible with social adaptation. The conclusion summarises the most important insights.

2 Comparative and Non-comparative Characteristics, Traits and Abilities

Characteristics, traits and abilities are distributed differently among people. Some follow a particular distribution structure, for instance a normal distribution. One example of a normal distribution is intelligence. Others, for example their sex, are distributed categorically. One is either—in most cases at least—female or male. Finally, there are such that do not follow any particular distribution structure among people. They are predominantly intrinsic, i.e. come from within and are not, or are only slightly societally or socially influenced. One example of such a characteristic, trait or ability is pain threshold or sensitivity to pain.

Different characteristics, traits or abilities not only follow different distribution structures. Their impact on human well-being also varies. With some it is relevant to well-being where one stands within the distribution among others. For example, it is usually disadvantageous to be much shorter or much less intelligent than the societal average. Having less of such a characteristic, trait or ability—measured according to the distribution among people in society—leads to a *relative* disadvantage. Empirically speaking, this correlation is relatively stable for different

[2] The most we can say in this case is that the individual has little or no reason to evaluate his or her life as a bad life. This does not change, however, the fact the individual does not endorse its life, and this may influence our perspective on this particular individual's well-being.

[3] The 'normal species functioning' approach goes back to Boorse (1975). There Boorse defends a naturalistic theory of health. Contrary to his view, the view that all judgments of health are or include value judgments is called normativism. According to Boorse, health in the theoretical sense is value-free. In the practical sense, "health is desirable insofar as it promotes goals one can justify on independent grounds" (ibid., pp 61). These include e.g. the desirability for its bearer. In what follows, I concentrate on Daniels' (2001) interpretation of the 'normal species functioning' account as he explicitly connects it to a theory of justice and thus to moral considerations, among them questions of a good human life.

characteristics, traits or abilities occurring among people in a particular way—often in a normal distribution.

In empirical terms, the impact on well-being of a categorically distributed characteristic, trait or ability does not follow a clear, determined pattern, but is predominantly subject to social, societal or cultural factors. Whether or not it is disadvantageous to be female, for example, largely depends on societal developments and cultural traditions.[4] In contrast, the impact of a comparative, non-categorical characteristic, trait or ability empirically follows a normal distribution (albeit often somewhat distorted or shifted). Because it occurs naturally, this correlation is neither imperative nor inevitable. Nevertheless, empirical observations have shown it to be relatively stable. Since the distribution among people is gradual, in contrast to comparative categorical characteristics, traits or abilities, it seems obvious to assume that the impact on well-being will follow the same rules. It can be shown that the impact is also largely dependent upon societal evaluation processes, and thus upon contingent historical and cultural factors. What is considered beautiful today, may not be tomorrow. And whether a certain height is advantageous or disadvantageous partly depends on how tall or short the other people in that particular society are.[5]

If a characteristic, trait or ability is non-comparative, then it has an *intrinsic* impact on well-being. This means that societal or social influences do not, or at most marginally, play a role for well-being. This is particularly clear taking the example of sensitivity to pain. Pain reduces well-being independently of whether or not other people are also in pain.[6]

As already mentioned, the difference between a comparative and a non-comparative characteristic, trait or ability is significant because the impact on well-being is considerably different. Whereas the former brings about a *relative* reduction in well-being, the latter involves a *non-relative*, drastic reduction in well-being (Schramme 2013). However, in the bioethical debate about well-being, for instance, there is frequent confusion concerning comparative and non-comparative characteristics, traits or abilities, as well as their impact on human well-being. In this debate, many characteristics, traits or abilities are viewed as if their impact on human well-being were exponential: as if having more of them would be conducive to increased well-being. For Julian Savulescu (2001), for example, intelligence is one such characteristic. He is of the opinion that it is definitely better to be more intelligent than less intelligent. The underlying assumption is that intelligence definitely increases human well-being. If therefore, in a hypothetical scenario, we have the choice between three embryos, one with an IQ of 70, one with 110 and one with 170, then according to Savulescu (ibid.) we would do best to select the one with an IQ of 170. For this embryo, in his view, promises—*ex ante*[7]—the best prospects of achieving the best life in absolute terms.

Intuitively speaking, many things initially favour this assumption. It has also been backed up empirically, at least in part. Satisfaction, social integration, the quality of personal relationships, the absence of mental diseases—these are all factors which have been positively linked to intelligence. They are important elements of every plausible account of objective well-being and not only valued subjectively (Gottfredson and Deary 2004; Neisser et al. 1996; Whalley and Deary 2001). *Vice versa* it is also true that mental disabilities increase the risk of psychiatric illness (Einfield and Tonge 1996; Tonge et al. 1996) and thus again not only affect the subject's evaluation of its own life, but also other elements of an objective account of well-being, e.g. health. Different studies have come to the following approximate conclusion: intelligent people tend to have personal relationships they assess as more valuable, tend to feel better integrated socially and tend to suffer from fewer mental disorders and diseases than less intelligent people. They also have a better education, are happier in their relationships and earn more money, enabling them to enjoy a higher standard of living. They are healthier and have a longer life expectancy. If one then proceeds to assume that these and other factors are important constituents of human well-being, then the conclusion seems obvious that it is better to be more

[4] In India, for example, being female tends to be detrimental to well-being. Not only are the risks of being aborted, killed or raped far higher for females than for males; in Indian society women are also at a disadvantage compared to men with regard to education, healthcare and employment (Sen 1990).

[5] This can also be seen from how well or badly a society is equipped to cope with the needs of certain people. A particularly impressive example of this is an historical study of acquired deafness in Martha's Vineyard, and the adaptation of an entire society to the needs of its deaf citizens (Groce 1985).

[6] At face value, pain might have an important warning function for human beings. To this extent pain is an important feature of the human body and does not exist for no reason (indeed, it is sometimes crucial for survival). And the impact of pain on human well-being is, of course, also dependent upon the strength, intensity, duration and outcome of the pain experienced. Strong pain is more debilitating than weak pain. Long-lasting and intensive, chronic pain is worse than brief and less intensive pain. When the outcome of pain is the birth of a child, this is also to be evaluated differently than, for example, phantom pain following the loss of a limb. Nevertheless, sensitivity to pain is a largely intrinsic, non-comparative ability. One might say that pain (except in its metaphorical sense, for example pain at parting) can be causally classified as a pathological aspect of human ability to function.

[7] Other characteristics, traits or abilities and environmental factors, as well as potential later influences—for example upbringing, school or medical care—are excluded from the *ex ante* observation.

intelligent than less intelligent. This results in the assumption that the best life is the one with the highest intelligence possible.

However, it has also been shown that the link between well-being and intelligence is not correct in absolute terms. Well-being does not *per se* increase exponentially with intelligence. Empirical studies about the lives of exceptionally intelligent people (with an IQ above 160) have shown that well-being does not increase with a high IQ, but actually decreases (Persson 2007). People with exceptionally high intelligence often feel socially isolated, have mental problems and display apathetic behaviour towards their surroundings. In addition, their actual performance also frequently falls short of their performance potential (Gross 2004).[8] Very high intelligence, or even just intelligence as an example of a comparative, non-categorial characteristic, is thus able to demonstrate what is probably also true of many other such characteristics, traits or abilities (such as height or physical strength, as well as emotional abilities like empathy, etc.): having more of it is not always better. And this is probably also true *vice versa*: having less is not necessarily worse. Again, it is important to mention that not only the subjective evaluation of own's life is affected, but (maybe resulting in) a detriment of other objective elements of human well-being such as health or having social relationships.

Now these arguments might stand up regarding the distinction between comparative and non-comparative characteristics, traits or abilities. But do they still hold true for impairments, or for the distribution of characteristics, traits or abilities on the negative side of an X curve? Is an impairment not always linked to a massive reduction in well-being, i.e. not just in relative terms?

3 Comparative and Non-comparative Impairments and their Impact on Human Well-Being

First of all, a more or less normal distribution of a characteristic, trait or ability will contain negative values as a matter of course. Once again, a telling example is intelligence. Taking the definition used by the American Psychiatric Association (2000), an IQ of 70 or less amounts to a mental impairment. And there is actually empirical evidence showing that the well-being of those with a mental impairments is at least at risk (Tonge et al. 1996). Many people with mental disabilities have psychiatric problems or develop psychiatric illnesses over the course of their lives (Holland 1999). This again, in my account, is not only relevant because people with mental problems are not likely to endorse their life subjectively, but because (mental) health is an important element of objective well-being.

This finding does not mean, however, that a mental impairment (or other impairments) automatically leads to a massive reduction in well-being. It is additionally unclear how many impairments, or which ones, are detrimental to well-being in absolute terms, i.e. substantially reduce well-being. A whole series of impairments exists for which this correlation is not true, or at least it is doubtful whether the correlation has not changed in historical perspective. A good example is Down's Syndrome. Not only has the life expectancy of people with Down's Syndrome improved dramatically over the past few decades, but their well-being has also increased considerably with growing medical care and education (Glasson et al. 2002). Consequently, when questioned today, people with Down's Syndrome usually report high subjective satisfaction with their lives (Roizen and Patterson 2003). In my opinion there is no *prima facie* reason strong enough to doubt the truth of these statements. Quite the contrary, concerning rising standards, e.g. regarding health care and education, people with Down's Syndrome nowadays have reasons to endorse their life, at least better reasons than they had a few decades ago.

We therefore have to look to other, far 'worse' impairments to find a serious impact on well-being. The first pressing candidates are those impairments where not even the most elementary prerequisites for an intrapersonal evaluation of well-being are given. These are impairments where even the basis of a subjective evaluation is non-existent, and thus also the prerequisites for being able to assess and report one's own well-being. With these impairments, the subjective conditions necessary for evaluating different states of being do not exist. Individuals with such impairments are not in a position to distinguish between a state X and a state Y or to react to them with subjective expressions of comfort or displeasure.[9] Not being able to experience or assess one's life, however,

[8] The reasons for reduced well-being in the highly intelligent—compared to less intelligent people—can be intrinsic. For example, people with much higher intelligence can feel alienated from their surroundings because they have no adequate conversation partners. But other, contingent reasons can also play a role. For example, poorly adapted environments—such as a lack of encouragement at school or a shortage of challenges professionally—can also lead to reduced well-being.

[9] At this juncture it is important to understand that these characteristics, traits or abilities are not exclusively or predominantly cognitive. Prerequisites include, for example, sensory abilities or basic forms of perception and communication. Therefore, excessive intelligence is not required in order to be able to evaluate different states. Even infants are capable of doing this. They express states such as hunger, thirst or tiredness with various forms of screaming or crying.

poses a serious objective problem and does not only affect the subject's problem to endorse its life.

A particularly severe type of an impairment which involves the absence of these prerequisites is anencephaly. Children born with this condition do not possess the anatomic structures for sensory processing, cognition or motor coordination. In addition, they have no capacity for sensory perception (Wilkinson 2006). If these elementary abilities are lacking, it is possible to speak of an absolute reduction in well-being: the prerequisites for evaluating well-being do not exist. Even the categories needed to apply the concept of well-being are missing. In other words: application of the concept of well-being does not make any sense here.

Beyond this clear-cut case, however, further criteria are required before a massive reduction in well-being can be assumed in conjunction with an impairment. In searching for such criteria, the following process suggests itself. We can ask which impairments increase the *burdens* of a life so tremendously (for example by involving extreme pain or other intrinsically induced physical suffering) that, as a result, well-being is reduced in absolute terms. Possible gains to be had from the impairment or from other existing characteristics, traits or abilities are unable to outweigh these burdens. Disabilities could thus be considered where the impairment leads to such comprehensive limitations that compensation (for example through other abilities) or treatment by other means (for example the provision of medical aids and appliances or rehabilitation) cannot provide any noteworthy increase in well-being. In the following I would like to present two possible candidates for such an impairment with intrinsic limitations. They demonstrate how at least the severe strains of these impairments mean absolute reduction in human well-being, thus fulfilling the criteria above.

The first disability is epidermolysis bullosa, a severe congenital and genetic skin disease (Ultto et al. 1997). The cause is a congenital mutation in certain genes, the products of which (including proteins) are necessary for the intact cellular structure of the skin. The mechanical link between the different skin layers is insufficiently formed. Depending on the development of the disease, blisters and wounds with scarring emerge on and in the whole body, including the mouth and oesophagus. In particularly severe forms of the disease, which can already be diagnosed at birth, the internal organs are also affected. These forms usually lead to an early death or take a progressive course. This disease undoubtedly involves great pain. With regard to their evaluation of their own life, human sufferers report extreme limitations in different areas of life (Horn and Tidman 2002). The more severe the disease is, and the larger the skin areas affected by it are, the greater the limitations reported (Tabolli et al. 2009).

A second impairment which could fulfil such criteria is Tay-Sachs disease. It leads to advancing reduction in cognitive skills, deterioration of psychomotor skills, paralysis, spasticity, blindness, deafness, cramps, a cherry-red macula in the retina and, within a few years, to death. Diagnosed children usually die by the age of two or three. They develop retrogressively until comatose and then die (Fernandez Filho and Shapiro 2004). This disease also involves intrinsic limitations, for example extreme pain, as well as extensive loss or deterioration of key human abilities. It is also so severe that it inevitably leads to death within just a few months or years.[10]

In empirical surveys, those affected by the particularly severe strain of epidermolysis bullosa RDEB-HS report particularly low subjective well-being (Ultto et al. 1997). Again, these subjective views are backed up by objective reasons. The affected individuals can hardly move, have almost no possibilities to build relationships and experience severe health problems associated with their condition. In severe cases at least, I believe it is possible to argue that the burdens of such a life easily exceed any potential gains. Suffering cannot be compensated for and is not or is barely mitigated by medical aids or other external factors or resources. In other words, the attitude and help of the outside world to this impairment takes away nothing or very little of its negative intrinsic quality.

In summary, the following can be said about the connection between impairment and well-being. Firstly, there are impairments where application of the term to well-being makes no sense, in that the individual characteristics, traits or abilities required to evaluate well-being are not given. Therefore, purely for conceptual reasons, it makes no sense to speak of well-being. Secondly, there are cases in which the burdens of an impairment easily outweigh any potential gains, and where no social endeavours can combat them or compensate for them. These impairments are also severe with regard to their impact on well-being.

These two categories of impairment where a massive reduction in well-being can be spoken of seem to be comprehensible. We can evaluate cases according to whether the burdens are greater than the gains. But this alone does not provide us with reasons for a moral link between characteristics, traits or abilities and impairments on the one hand, and human well-being on the other. In the

[10] Both impairments are without a doubt severe, and yet regarding their impact on well-being they cannot be equated to anencephaly. In the latter it can be shown that the elementary prerequisites for well-being are missing, so that the mere application of the term or concept well-being seems to make little sense. In contrast, it is possible to speak of well-being with both epidermolysis bullosa and Tay-Sachs disease, in the sense that the term or concept of well-being can plausibly be applied. Those affected by these impairments are capable of reporting—even though voicing may not always be possible (for example with Tay-Sachs)—the evaluation of their own well-being.

following I will present two approaches which attempt just this, before ultimately rejecting them in favour of a proposal of my own.

4 Normal Species Functioning, All Purpose Means and Communities of Disabled Human Beings

The two approaches which I would like to present and then reject are the 'normal species functioning' approach (Boorse 1975; Daniels 2001) and the 'general purpose means' approach (Buchanan et al. 2000).

The 'normal species functioning' approach interpreted by Norman Daniels (2001) does not presume a direct link between disease or impairment and well-being. Rather, he attempts to connect well-being anthropologically to functional abilities of the human species, to its physical structures and physical functions. For him, the special moral significance of healthcare (but also food, shelter and other resources undoubtedly necessary for well-being) results not directly from its contribution to the well-being of human beings, but from its contribution to so-called 'normal human functioning'. This in turn provides the objective basis needed for potential well-being. According to Daniels, the moral and social obligation is to provide institutions which safeguard this potential. He writes: "Disease and disability, both physical and mental, are construed as adverse departures from or impairments of species-typical functional organization, or 'normal functioning' for short. The line between disease and disability and normal functioning is drawn in the relatively objective and nonevaluative context provided by the biomedical sciences, broadly construed (though glaring misclassifications have also occurred)" (Daniels 2001, pp 3).

In his opinion, progress in biomedicine has given us objective indications for whether or not disease or disability conflict with so-called normal human functioning and, consequently, lead to a reduction in well-being. Daniels' definition thus, on the one hand, makes it clear that the reference point for evaluative efforts is ultimately the species-typical functioning of human bodies. On the other hand, it becomes clear that this description contains an important normative purpose, as well as a definition of human well-being.

In a second proposal for defining the relationship between well-being and human functioning or impairment, a different path is chosen. The 'general purpose means' approach favoured by Buchanan et al. (2000) attempts to link human well-being to goods which are key to all conceptions of human well-being. Buchanan et al. (ibid. pp 167) write: "The typical human's capacity for sight may be thought of as a general-purpose-means—useful and valuable in carrying out nearly any plan of life or set of aims that humans typically have. It is a 'good' not only from a distinct perspective or plan of life that some may adopt but many others may reject. Instead, there are few perspectives from which the loss of sight is not a harm, and few perspectives from which having sight is not a benefit in carrying out the plan of life a person has adopted." It is therefore not the difference between 'harm' and 'benefit' which is relevant, but between 'general purpose means', important for all human beings and nearly all plans of life and whose loss is connected with suffering for all plans of life, and the means whose value and significance depend upon exactly which plans or interests one would like to pursue. According to Savulescus (2001), examples of 'general purpose means' are hearing, seeing, the ability to concentrate, to interact with other human beings and to respond to others with empathy.

In my opinion, both approaches must be deemed inadequate for determining which impairments lead to massive reductions in well-being, and for which reasons. First of all, the normative connection claimed in the 'normal species functioning' approach between species-normal abilities, i.e. those to be biologically expected, and human well-being is controversial. Two reasons can be given. Firstly, the extent to which the possession and execution of certain abilities contribute to well-being it is not clear *per se*. Many human characteristics, traits or abilities are part of the normal biological equipment of the human species and thus to be expected, without their absence necessarily meaning a reduction in well-being.[11] And secondly, the metaethical question remains of why a descriptive functional characteristic, trait or ability of the human body would lead *per se* (and without further philosophical assumptions) to a normative conclusion, namely the assumption that an impairment involves a massive reduction in well-being.[12]

Other factors also lead to rejection of the proposals by Daniels (2001) and Buchanan et al. (2000). The correlation between species-typical functioning and human well-being is just as contingent and non-imperative as the impact or significance of certain characteristics, traits or abilities for

[11] It is species-typical, for example, to be able to waggle one's ears or roll one's tongue. Hardly anybody would go so far as to maintain, however, that well-being is minimised when these abilities are missing. Rather, it seems obvious to assume that there are certain, key human characteristics, traits or abilities which are essential to human well-being. Others are not essential, even though they might be part of the 'normal' equipment of the human species.

[12] It is important to keep in mind that these problems cannot be solved by only referring to what is bio-statistically normal human functioning. Firstly, there is a missing link between the descriptive and the normative. Secondly, even if we have substantial knowledge of which functionings affect certain elements of human well-being, e.g. health, this information in itself does not tell us how and to which degree human well-being is affected.

a good life. Some of them, such as seeing, hearing or walking are undoubtedly linked to well-being in that they open up to us a host of chances and possibilities in life which we would not have if we did not possess them. But it is not true that well-being is automatically given when we possess these characteristics, traits or abilities. In addition, manifold empirical findings regarding the well-being of blind, deaf or lame people emphatically show that in many cases impairments can be compensated for, and new options found regarding perception, comprehension or mobility.

Characteristics, traits or abilities such as intelligence undoubtedly make an important contribution to human well-being. But this is not sufficient proof that possessing a maximum of these characteristics, traits or abilities would also mean a maximum of well-being. Also, in many cases it is only in isolated observation—i.e. abstracted from environmental influences, as well as from any other characteristics, traits or abilities possessed by the individual—that it is safe to assume that loss or absence of a characteristic, trait or ability would lead to a massive reduction in well-being. The possession or execution of certain characteristics, traits or abilities does seem to be useful for many plans of life. But this neither shows that their absence is incompatible with well-being (because, for example, they cannot be compensated for), nor makes it clear without further normative assumptions how many of these characteristics, traits or abilities it is necessary to have in order to achieve well-being.

The two approaches therefore have to be rejected. Which leaves the reasons for assuming a massive reduction in well-being in conjunction with certain impairments still unanswered. In the following I would like to put forward a proposal of my own. The approach I advocate demands the existence of a community of disabled people, all with a certain disability, who would like to be integrated in society and certain groups with or despite this disability. Before I describe this approach in more detail, it is important to understand that it requires assimilation of the idea of a 'life lived from the inside'. This again means that well-being results both from the possession of certain goods, cultural, societal and social evaluations and modes of recognition—i.e. a comprehensive series of external conditions—and from an internal evaluation, as well as from life as a whole. Life has to be lived from the inside out; one has to identify oneself with the life one leads. If this is not the case, it is not possible to speak of well-being in a comprehensive sense, however many goods or abilities may exist objectively. In a paper on the intrinsic significance of education, Brighouse (2006) expressed this idea as follows: "For somebody actually to flourish, they have to identify with the life they are leading. They have to live it from the inside, as it were. Now someone can know that their way of life suits them without knowing or thinking much about alternatives, so they don't have to think critically about the alternatives in order to identify with their life. But they must, at the very least, not experience their way of life as being at odds with their most fundamental experienced interests and desires." (Brighouse 2006, pp 16).

Descriptions of 'life from the inside' can be found in sociological studies, such as those by Williams (1998), and in philosophical ones, such as those by Carel (2008). They amount to phenomenologically consolidated descriptions of life with disability, as well as the resulting normative requirements regarding the safeguarding of well-being for disabled people. They convey the thoughts and evaluations of subjects, but at the same time are intersubjectively comprehensible and based on objective reasons. These phenomenological descriptions of disabled life are, on the one hand, theoretically valuable because they enable people not affected by disability to form an idea of what leading such a life entails, in all its facets. Phenomenological approaches do not highlight characteristics, traits or abilities in isolation, together with an equally artificially isolated impact on human life, as is often the case in analytical approaches. Rather, they assume that a life is always lived through the coaction of very different characteristics, traits or abilities, circumstances, resources, relationships, etc., and ultimately needs affirmation as relevant to one's identity.

As stated already, these phenomenological descriptions are in no way purely subjective. They do not embody the personal diaries of individual people. Far more, through their consolidated description they open up the possibility of intersubjective communication, namely between those affected, who can recognise themselves in the descriptions, and those non-affected, who can join in with empathy. This access is significant from a life-world point of view as well. The significance of a life which is lived as affirmed and deemed good, together with a desire to lead a life integrated in society and in communities, also points to the practical significance of self-help groups for the disabled. In these self-help groups, precisely those processes occur which can enable disabled people to lead a good life in communities and in society, despite their impairment. The prerequisite for participation in a self-help group is the will and the desire to lead a good life integrated in society and different communities. If such a thing is no longer practically possible, or no longer sought after, then one may assume that the affected person no longer believes a good life to be possible.

The chance or the will to lead a life which a human being can personally experience as worthy brings us back to subjective evaluations of life and an individual's ability to evaluate life and express such evaluations. The latter is

not to be understood subjectivistically, in the sense of only valid for individual subjects. Far more one is to imagine, at least hypothetically, a community of disabled persons who would have to evaluate life with this disability and report the degree or extent of well-being it is possible to achieve with such a life. This type of intersubjective communication can seek reinforcement or back-up from multidimensional empirical studies investigating the well-being of affected persons and particularly focusing on the dynamics and mutual impact of intrinsic and extrinsic factors. Valuable insights into life with a certain disability can also be imparted by phenomenological studies, however, with their consolidated descriptions enabling us to gain an insight into what life must be like with a disability.

What could be achieved for the issue at stake here by adopting this approach? My belief is that it would enable disabilities to be described and ultimately understood and evaluated normatively. The extent to which well-being would be reduced by a particular impairment in absolute terms could then be explored, at least as a mental experiment: it is reduced when we can no longer imagine a group or community of people sharing the same impairment who affirm their life and—despite all the burdens posed by it—ultimately believe it to be good.

5 Conclusion

In exploring the issue of which disabilities are detrimental to human well-being and for which reasons, I have addressed two misunderstandings. Firstly, the frequent sweeping generalisation that disability is an example of reduced well-being in an absolute sense. Here it is crucial to specify which disability is meant because the impact on well-being can assume very different shapes and qualities. Secondly, the confusion of comparative and non-comparative or absolute viewpoints regarding human well-being. Here, too, I have attempted to show that argumentation needs to be more precise than is often the case, for example in the bioethical debate.

There may be good reasons for claiming that it is better not to be disabled than to be disabled. And yet this is not proof that being disabled is bad for the affected person in an absolute sense. A disability is only bad for a person in an absolute sense if it denies that person a minimum of elements absolutely crucial to human well-being. I have attempted to show this using a mental scenario and asking whether or not we can imagine a hypothetical community of affected people all sharing the same fate who would deem their life incompatible with a good life, not just subjectively, but also in a manner which is comprehensible intersubjectively. Provided this is not the case, those affected by a disability seek contact to one another and allow their lives to be described in a consolidated phenomenological manner. Such descriptions, for example by Carel (2008), report both the burdens of a life with disability and its positive sides.

The negative side reveals that the most severe forms of mental disability, for example anencephaly, are disabilities where application of the term well-being makes no conceptual sense. In these people the structural prerequisites for feeling and evaluating well-being are lacking. And such impairments exist, such as Tay Sachs or severe strains of epidermolysis bullosa, in which the burdens of the disability exceed, or at least can exceed the potential gain or potential compensations.

My own proposal, presented after a rejection of the proposals by Daniels (2001) and Buchanan et al. (2000), is admittedly vague, and in two respects. Firstly, its practical significance requires more detailed formulation with regard to certain historical and cultural realities. Secondly, it is of theoretical interest and open to empirical investigation. However, the exact relationship between empirical approaches and the phenomenological view of disability still requires precise, in-depth research.

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